

Opening

Bernard KOUCHNER, former Minister | France

From being a passive patient to a proactive patient in the French health system

In the 1990s, the patient, who by definition had a passive role in the health system, saw his prerogatives grow. At that time, the AIDS epidemic and the various health related scandals raised questions about the knowledge of doctors, thus launching the debate on patients' rights. The very term "patient" was then called into question, as the patients were no longer those who "had to be patient" but the stakeholders and designers of the health system. At the heart of this revolution, the General Health Assembly (les Etats Généraux de la Santé), launched in 1998, set up a citizen consultation to listen to the proposals, needs and demands of individuals and institutions regarding the health system in France.

The General Health Assembly as a marker of the genesis of the patient's right to health, still incomplete.

These consultations led to the emergence of laws that constitute the core of patients' rights and more precisely:

- **The right to therapeutic decision-making.** The law resulting from the General Health Assembly provides that the therapeutic decisions are taken jointly with the patient.
- **No fault compensation:** since the General Health Assembly, the liability in case of fault is framed, giving more responsibilities to the health workers in comparison with the previous framework which gave whole responsibility to the hospital management. The ONIAM (National Office for Medical Injury Compensation; *Office National d'Indemnisation des Accidents Médicaux*), created on this occasion, organises the process of compensation for patients affected by no-fault accidents.
- **The patient's right to information.** The patient record now belongs to the patient who can request it on leaving the hospital. This right to information has since been extended thanks to the assumption of responsibility for medical information by the national health insurance system.
- **The end of the patient's life.** This debate, which was initiated during the General Health Assembly, is still relevant today. The main fear then was that the right to assisted euthanasia would become a common practice, for example in the case of a shortage of beds. This subject is one of the debates that did not reach a conclusion during the General Health Assembly.

Patients' rights need to be consolidated: a discussion to be held at the French National Council for Health Refoundation

Despite the improvements in patients' rights resulting from the General Health Assembly, patient information remains a major issue today. The reliability of the abundant medical information available on the Internet must be certified by the State, and individuals must be educated about their rights so that they can exercise them. The information gives the possibility to make different choices. First, he/she can choose the doctor who will take care of him/her, based on the error rate of the latter and the number of procedures he/she performs per year. Also, he can choose the type of care he/she receives, based on exhaustive information on the effects and consequences of the patient's life habits. This issue of patient information will have to be debated at the National Council for Health Refoundation, just like the question of the right to the end of life, which this time will perhaps lead to a legal decision.